Very low birthweight (less than 1,500 grams) and intermediate low birthweight (1,500-2,499 grams) babies were born with congenital anomalies more often than their counterparts weighing 2,500 grams or more. In 1990, 21.1 percent of the very low birthweight infants were born with a congenital abnormality. In comparison, only 5.6 percent of all babies weighing over 2,500 grams were reported to have congenital anomalies in 1990. The increased likelihood of patent ductus arteriosus and lung hypoplasia associated with preterm infants probably accounts for much of the difference between very low birthweight and normal birthweight infants.

The number and percentage of infants in the state who died within their first year of life, and who had been diagnosed with a congenital anomaly, increased from 1988 to 1989. In 1988 and 1990 respectively, 27 percent and 29 percent of all infants who died within the first year of life had been diagnosed with one or more congenital anomalies. In about one-third of these cases, however, birth defects were not reported to be the underlying cause of death. The percentage of infants who lived through their first year of life and had at least one congenital anomaly increased from 4.3 in 1988 to 5.9 in 1990. Again, part of this increase is due to better ascertainment of congenital anomalies beginning in 1989.

CAUTIONS IN DATA INTERPRETATION

The Registry data prior to 1989 have some limitations. One limitation is the incomplete hospital discharge data in the 1984-88 Registry files. Because of the "pockets" of missing hospital discharge data in certain parts of the state, the Registry data prior to 1989 may underestimate the occurrence of certain types of congenital malformations in particular regions or counties of North Carolina. Since the newborn hospital discharge data is a major contributor of infant birth defect data, it has been useful to determine where the "pockets" of missing data are located. Figure 1 shows the counties that had complete birth defect reporting, partial reporting, and no reporting in 1988.

A second limitation is the under-reporting or incompleteness of birth defects data. For example, the birth certificate and newborn hospital discharge databases record birth defect diagnoses made during the newborn period only, and are poor sources of data for conditions that are generally not diagnosed until after the infant is discharged from the hospital of birth.

Thirdly, the hospital discharge data are primarily collected for insurance reimbursement and other purposes, and are not coded in a format that is most desirable for etiologic studies. Hospital discharge summaries record up to five diagnoses, so if an infant has more than five birth defects and/or other health conditions, some diagnoses are lost when the original hospital record data are transferred into the hospital discharge database format. Despite these data limitations, ascertainment of many of the more severe malformations, such as spina bifida, renal agenesis, and hypoplastic left heart syndrome, appears to be relatively good. The rates for these defects are comparable to those reported by the National Birth Defects Monitoring Program.

When studying a public health problem, such as the occurrence of birth defects, counts and rates are used as tools for evaluating the extent of the problem. An incidence rate measures the occurrence of new cases of disease in a community, and is useful in helping to determine the need for initiation of preventive measures. "The term rate, although there are some exceptions, is usually reserved to refer to those calculations that imply the probability of the occurrence of some event".[4] Any rate with a small number of events in the numerator will be unstable, with possibly large random fluctuations from year to year that do not comprise a significant trend. It has been shown that events of a rare nature follow a Poisson probability distribution. A useful rule of thumb is that any rate based on fewer than 20